Supported Decision-Making and Community Based Supports

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Important Characteristics for all HCBS Settings

- Integration with the Community
- Choice
- Rights
- Independence

2

Final Rule will Ensure:

- Each individual gets the most out of community living
- All services are provided in integrated settings
- Provision of services is person-centered

3

Rule Includes Two Provisions

Home and Community Based Service Settings

- Increase protections relating to where individuals receive Home and Community Based Services
- Ensure individuals are afforded opportunities to be fully integrated into their community

Person-Centered Planning Process

- Increase individual's input on how services are planned and what is included in the plan.

4

Relationship of Guardianship to the HCBS Final Rule

42 C.F.R. Part 441, Sub-part G, states the Intent of the Final Rule:

*"To ensure that individuals receiving LTSS through HCBS programs have **full access** to benefits of community living and the opportunity to receive services **in the most integrated setting appropriate**"*

Requirements of the Final Rule include:

1. *Settings that provide opportunities to seek employment and work in competitive integrated settings, engage in community life, and control personal resources.*
2. *A lease or other legally enforceable agreement*
3. *Lockable entrance doors*
4. *Choice of roommates and privacy in their sleeping or living unit*
5. *Choice of visitors at any time*

5

Relationship of Guardianship to the HCBS Final Rule (cont.)

Modifications of these requirements must be:

1. Supported by specific assessed needs
2. Justified in the person-centered service plan
3. Documented in the person-centered service plan
4. The responsibilities of a legal guardian or other person authorized under state law to make decisions for the individual must be spelled out in the person-centered service plan.

6

Balancing the intersection of health/safety/choice and person centeredness

- Use the PCP process including assessments, pre-planning, planning and follow-up
- Technology: Increases independence, self-efficacy, and self-esteem while providing safeguards
- The new rule not only permits these levels of autonomy and risk, they require it.

7

Models that Hinder Implementation of Final Rule

1. Continuum-implies that there is something other than real community/settings where someone should live, work or play – an array of services model using LRE

- Least restrictive implies restriction is acceptable
- Supports primacy of professional judgment
- Implies person must physically move with change/development
- Directs attention to physical settings

8

Models that Hinder Implementation of Final Rule (cont.)

2. Readiness or "pre"-implies that there is a place at which one can graduate to a service level, usually residence, classroom or job

- If an individual does not like setting they are in
- Individual in pre-vocational service that is 64 years old
- Supports do not follow the person – model is vice versa

9

Settings Final Rule 2019 Implementation

HCBS Waiver participants have had similar rights for many years via

- ADA 1990
- Olmstead 1999
- Some State Policy/Regulations

The rights to privacy, choose friends and choose roommates in literature/thinking:

- These rights have been in the public eye since Burton Blatt exposed institutional life in the late 1960's
- These rights/lifestyles have been promoted since Bengt Nirje and Bank Mikkelsson and in the U.S. Wolf Wolfensberger's Normalization principle since the early 1970's

10

Resources for More Information

- Bazelon Center
  http://www.bazelon.org/news-publications/press-releases/hcbs-settings-rule.aspx
- State Medicaid Office
  - State specific transaction plans
  - Guidance regarding 'settings that isolate'
  - Summary of Regulatory Requirements
  - Information on 'heightened security' to determine integration
  - Questions that may assist in assessment of residential and non-residential settings
- CMS – Center for Medicaid and Medicare Services

11

Community-Based Supports for Supported Decision-Making: Using the PRACTICAL Tool

Erica Wood
Commission on Law and Aging
American Bar Association
August 2016

The PRACTICAL Tool – ABA Partner Entities

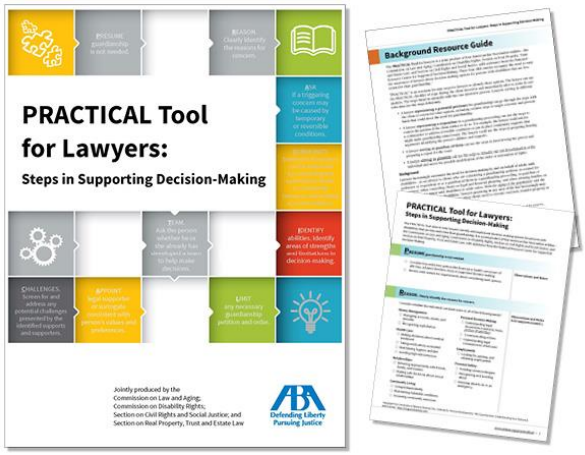
The PRACTICAL Tool aims to help in identifying and implementing decision-making options for persons with disabilities that are less restrictive than guardianship. It is a joint product of four American Bar Association entities:

- Commission on Law and Aging
- Commission on Disability Rights
- Section on Civil Rights and Social Justice
- Section on Real Property, Trust and Estate Law

The Tool was produced with assistance from the National Resource Center for Supported Decision-Making

2

New ABA Tool on Supported Decision-Making



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Background for PRACTICAL Tool

"PRACTICAL" is an acronym for nine steps to identify decision-making options.

You can use the PRACTICAL checklist of steps during client interviews and immediately after to assist in case analysis.

The steps blend in naturally with the case interview process.

Professionals and advocates serving in different roles may use the steps differently.

4

PRACTICAL Tool

P = **Presume** guardianship not needed

R = **Reason.** Identify reason for concern

A = **Ask** concern is caused by temporary/reversible conditions

C = **Community.** Determine if concern can be addressed by community/family resources, accommodations

T = **Team.** Ask whether person already has a team

I = **Identify** abilities and limitations in decision-making/need for support

C = **Challenges.** Screen for and address potential challenges with supports & supporters

A = **Appoint** legal supporter or surrogate consistent with values

L = **Limit** any necessary guardianship petition & order

5

PRESUME guardianship is not needed.

- Consider less restrictive options like financial or health care power of attorney, advance directive, trust, or supported decision-making
- Review state statute for requirements about considering such options

6

REASON. Clearly identify the reasons for concern.

Consider whether the individual can meet some or all of the following needs:*

Money Management:
- Managing accounts, assets, and benefits
- Recognizing exploitation

Health Care:
- Making decisions about medical treatment
- Taking medications as needed
- Maintaining hygiene and diet
- Avoiding high-risk behaviors

Employment:
- Looking for, gaining, and retaining employment

Relationships:
- Behaving appropriately with friends, family, and workers
- Making safe decisions about sexual relationships

Community Living:
- Living independently
- Maintaining habitable conditions
- Accessing community resources

Personal Decision-Making:
- Understanding legal documents (contracts, lease, powers of attorney)
- Communicating wishes
- Understanding legal consequences of behavior

Personal Safety:
- Avoiding common dangers
- Recognizing and avoiding abuse
- Knowing what to do in an emergency

**Adapted from University of Missouri Kansas City, Institute for Human Development, "MO Guardianship: Understanding Your Options & Alternatives," http://moguardianship.com.*

7

ASK if a triggering concern may be caused by temporary or reversible conditions.

Look for steps to reverse the condition or postpone a decision until the condition improves.

Are concerns the result of or related to temporary or reversible conditions such as:

- **Medical conditions:** Infections, dehydration, delirium, poor dental care, malnutrition, pain
- **Sensory deficits:** hearing or vision loss
- **Medication** side effects
- **Psychological conditions:** stress, grief, depression, disorientation
- **Stereotypes or cultural barriers**

8

COMMUNITY. Determine if concerns can be addressed by connecting the individual to family or community resources and making accommodations.

Ask "what would it take?" to enable the person to make the needed decision(s) or address the presenting concern. Might any of the following supports meet the needs:

Community Supports:
- In-home care, adult day care, personal attendant, congregate and home delivered meals, transportation
- Care management, counseling, mediation
- Professional money management

Accommodations:
- Assistive technology
- Home modifications

Informal Supports from Family/Friends:
- Assistance with medical and money management
- Communication assistance
- Identifying potential abuse

Residential Setting:
- Supported housing or group home
- Senior residential building
- Assisted living or nursing home

9

TEAM. Ask the person whether he or she already has developed a team to help make decisions.

- Does the person have friends, family members, or professionals available to help?
- Has the person appointed a surrogate to help make decisions?

10

IDENTIFY abilities.

Identify areas of strengths and limitations in decision-making if the person does not have an existing team and has difficulty with specific types of decisions.

Can the individual:

- Maintain consistent decisions and primary values over time
- Understand the consequences of decisions
- Make decisions and explain his/her reasoning

11

CHALLENGES.

Screen for and address any potential challenges presented by the identified supports and supporters.

Screen for any of the following challenges:

Possible challenges to identified supports:

- Eligibility, cost, timing or location
- Risk to public benefits

Possible concerns about supporters:

- Risk of undue influence
- Risk of abuse, neglect, exploitation (report suspected abuse to adult protective services)
- Lack of understanding of person's medical/mental health needs
- Lack of stability, or cognitive limitations of supporters
- Disputes with family members

12

APPOINT legal supporter or surrogate consistent with person's values and preferences.

Could any of these appointments meet the needs:

- Agent under health care power of attorney or advance directive
- Health care surrogate under state law
- Agent under financial power of attorney
- Trustee
- Social Security representative payee
- VA fiduciary
- Supporter under representation agreement, legally or informally recognized

13

LIMIT any necessary guardianship petition and order.

If a guardian is needed:

- **Limit guardianship to what is absolutely necessary,** such as:
  - Only specific property/financial decisions
  - Only property/finances
  - Only specific personal/health care decisions
  - Only personal/health care decisions
- **State how guardian will engage and involve person** in decision-making
- **Develop proposed person-centered plan**
- **Reassess periodically for modification or restoration of rights**

14

Questions?

PRACTICAL Tool and Resource Guide

http://www.americanbar.org/groups/law_aging/resources/guardianship_law_practice/practical_tool.html

15